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TITLE: Quality of Life and Cost of Care of Prostate Cancer

Patients

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CONTRACTING ORGANIZATION: University of Pennsylvania

Philadelphia, Pennsylvania 19104-6205

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### **Table of Contents**

Cover	
SF 298	2
Introduction	3
Body	3
Key Research Accomplishments	16
Reportable Outcomes	17
Conclusions	17
References	
Appendices	18-25

### REPORT DOCUMENTATION PAGE

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differential treatments	for prostate cancer f	or different eth	nic group	s. on quality of		
life and cost of care fo	r the elderly. Anoth	er issue of inte	rest is t	he comparison of		
efficiency and quality o	f care for prostate o	ancer offered in	two dist	inct health care		
systems: Veterans Affair	s (VA) and non-VA. Th	ree specific aim	s of this	study are: (1) to		
analyze and compare the	quality of life and s	atisfaction with	care of	prostate cancer		
patients across two ethn	ic (African Americans	and Caucasians)	groups,	controlling for the		
stage at diagnosis and c	o-morbidity; $(2)$ to a	nalyze and compa	re the av	erage costs of care		
diagnosis and as week's	of prostate cancer patients across two ethnic groups, controlling for the stage at					
treatment modelities and	diagnosis and co-morbidity; and (3) to analyze and compare the resource utilization, treatment modalities and cost-effectiveness of prostate cancer care between VA and non-VA					
hospitals During the f	irst year of this	r prostate cance	r care be	tween VA and non-VA		
Americans and Caucasians	hospitals. During the first year of this prospective we have recruited 292 (African					
oncology clinics. Univer	Americans and Caucasians) after their written consent from the Urology and radiation oncology clinics, University of Pennsylvania Health System and VA medical center.					
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#### INTRODUCTION

Due to uncertainty in the screening and treatment, debate on outcomes such as quality of and cost of care continues. Research has shown that the type of treatment received for a given stage of prostate cancer varies by ethnicity and age. Hence, the objective of this study is to assess the effects of differential treatments for prostate cancer for different ethnic groups, on quality of life and cost of care for the elderly. Three specific aims of this study are: (1) to analyze and compare the quality of life and satisfaction with care of prostate cancer patients across two ethnic groups, controlling for the stage at diagnosis and co-morbidity; (2) to analyze and compare the average costs of care of prostate cancer patients across two ethnic groups, controlling for the stage at diagnosis and co-morbidity; and (3) to analyze and compare the resource utilization, treatment modalities and cost-effectiveness of prostate cancer care between VA and non-VA hospitals. This study uses prospective cohort design to assess and compare, across Caucasians and African Americans, the health related quality of life (HRQOL) and cost of care for prostate cancer patients older than 65 years. A total of 280 subjects will be recruited from the urology and radiation oncology clinics at the University of Pennsylvania Health System (UPHS), and Philadelphia VA Medical Center. Baseline data will be collected within 1-2 weeks after recruitment, with subsequent follow up at three months interval for two years on demographics, clinical, HRQOL, and cost data. We will compare average cost of treatment and quality of life across two ethnic groups, controlling for stage and co-morbidity. Finally, Markov decision model will be used to analyze and compare cost-effectiveness of prostate cancer treatments across two ethnic groups and comparison will be made between VA and non-VA hospitals.

#### **BODY**

We finalized the research protocol and obtained approval from the Human Compliance and Quality, U.S. Army Medical Research and Materiel Command; the Regulatory Affairs, Institutional Review board, University of Pennsylvania; and the Research Services, VA Medical Center, Department of Veterans Affairs, Philadelphia. The process of recruiting newly diagnosed prostate cancer patients was initiated in February of 2002. The specific steps of this process are: (1)contacting the patients; (2) explaining the study; and (3) obtaining the consent.

### Task 1. Recruitment of Patients

- a. Potential patients were contacted at the urology and radiation oncology clinics after introduction by their urologist and radiation oncologist. Newly diagnosed patients were also contacted at their pre- prostatectomy classes, organized by the urology clinic. The newly diagnosed prostate cancer patients were contacted at the Veteran Affairs Medical Center during their urology clinic visit.
- b. Research assistant held a detailed discussion about the study with the patients
- c. Consent was obtained from interested patients
- d. Recruitment of patients
- e. A unique patient identifier was assigned to each patient. This information will be maintained as highly confidential at all times.

Table 1 shows the monthly recruitment pattern over the past eleven months of the study period. Some newly diagnosed prostate cancer patients were at the urology clinics for a second opinion only, and were not eligible for our study. So far, we have recruited 238 newly diagnosed prostate cancer patients from the University of Pennsylvania Hospital and 54 from the Philadelphia VA Medical Center.

Table 1: Recruitment of Newly Diagnosed Prostate Cancer Patients

Month Month	Hospital of the University of Pennsylvania		Philadelphia VA Medical Center			
	# of eligible	# recru	ited	# of eligible	# recruited	
	patients	<65	≥ 65	patients	<65	≥ 65
February 2002	18	5	10		0	0
March 2002	10	2	5	3	1	1
April 2002	29	7	9	6	1	2
May 2002	34	5	15	7	6	1
June 2002	54	4	20	10	4	4
July 2002	40	11	20	9	2	4
August 2002	19	5	7	8	2	2
September 2002	24	5	12	12	1	7
October 2002	52	13	24	9	3	2
November 2002	40	13	22	6	2	3
December 2002	24	13	11	8	4	2
TOTAL	344	83	155	78	26	28

Task 2: Preparation of Medical Record Abstractions

A medical record abstraction form was developed to extract clinical data such as PSA scores, Gleason scores, stage of cancer at the time of diagnosis, type of treat received and diagnostic procedures performed from individual medical records (Appendix A).

### Task 3: Base line Data Collection:

a. In the first eleven months of the study, we have concentrated on recruitment or newly diagnosed prostate cancer patients from the urology and radiation oncology clinics at the

University of Pennsylvania Health System (UPHS). We have also recruited patients from the Philadelphia VA Medical Center. After obtaining a written consent from the patient, we obtain his base line demographics and quality of life using the UCLA prostate cancer index and SF-36. The subsequent follow ups are to be done at three months interval for a period of two years beyond a patient's entry into the study. Data on following variables is obtained: Age, ethnicity, types of insurance, living arrangement, marital status and mortality. Clinical data collection via medical charts is currently ongoing. So far, for 44 patients, we have extracted clinical information such as: date of diagnosis, date of treatment & length of stay; type of treatment/procedures; hospital charges & reimbursements, number and type of medications; number of other procedures, principal DRG diagnostic studies and relevant medications.

b. A patient satisfaction survey was administered at the baseline and at follow-up.

### **Patient Follow-up and Retention**

### Task 4: Develop Plan for Follow-up Patient interview

a. A tracking system was developed to track patient recruitment and contact processes. During the follow-up period, three patients died, two were from the UPHS and one was from the VA. All the three prostate cancer patients died within three months of their study entry. Table 2 shows patient retention and follow-up. We provide each patient with \$10 in compensation at the time of recruitment into the study and \$5 at each successful follow-up. This has helped in generating good response rates.

	Baseline		seline 3 month		6 month	
	# patients recruited	# of surveys completed	# eligible for follow up	# of surveys completed	# eligible for follow up	# of surveys completed
HUP	238	226	154	145	84	73
VA	54	47	25	18	20	8

Task 5: Follow up interview and Health Related Quality of Life, and Cost (resource Utilization) Data Collection

- a. Surveys were sent out at every three months to collect data from enrolled patients.
- b. Non-respondents were contacted over the telephone and were offered the option to complete the survey instruments over the telephone.
- c. Data collection and data entry was done simultaneously.
- d. Date of diagnosis, date of treatment & length of stay, other relevant medical diagnoses and medications data are being obtained from medical charts.
- e. Health Related Quality of Life data was obtained using SF-36 and UCLA Prostate Cancer Index.

Table 3: Demographics of the study group (n=156)

Variable	Percent
Race	
Caucasian	121 (77.6%)
African American	35 (22.44%)
Education	
8 grades or less	4 (2.6%)
Some high school	11 (7.1%)
High school graduate	37 (23.9%)
Some college	31 20.0%)
College graduate	21 (13.6%)
Advanced or graduate training	50 (32.5%)
Marital status	
Married	123 (79.4%)
Single	10 (6.5%)
Widowed	6 (3.9%)
Divorced	16 (10.3%)
Current employment status	
Working full-time	81 (52.6%)
Working part-time	8 (5.2%)
Retired	53 (34.4%)
Other	10 (7.7%)
Household income	
Under \$10,000	6 (4.0%)
\$10,001 up to \$20,000	14 (9.3%)
\$20,001 up to \$30,000	15 (10.0%)
\$30,001 up to \$40,000	13 (8.7%)
\$40,001 up to \$50,000	8 (5.3%)
\$50,001 up to \$70,000	23 (15.3%)
\$75,001 or more	69 (46.0%)

The demographic characteristics of recruited patients are as shown in table 3. The mean age was 68.7 (sd.=4) years and the mean number of persons in a household was 2.4 (sd.=1.1) (please note that these are preliminary data and data input and data cleaning is currently ongoing).

Tables 3 to 5 present the demographics, general health and functional status of the newly diagnosed prostate cancer patients at the baseline for both UPHS and VA patients. Physical functioning (Table 4) is a measure of activities during a typical day and the score ranges from 10 to 30. Lower the score on physical functioning, the more limited the movements. A score on physical roles indicates problems with regular work and activities and the score ranges from 4 to 8. Lower score on this indicates more problems with regular activities. Social functioning is a measure of how physical health interferes with social activities with family, friends, neighbors or groups. A score varies from 2 to 10, 2 indicating no problem whereas 10 is a high problem. Bodily pain indicates presence of bodily pain and its impact on normal work and the score ranges from 2 to 11. A score of two mean no pain and a maximum score or eleven indicating extremely or very sever pain. Vitality measures level of energy and the score ranges from 4 to 24. Higher the score indicates better vitality. Mental health is a measure of emotional well being. The score on mental health ranges from 5 to 30. Higher the score indicates better mental health. Urinary function is a measure of urinary habits. The score varies from 5 to 19. Higher the score, better the urinary function. Bowel function indicates bowel habits and abdominal pain. The range of the score is 1 to 20. Higher a score on bowel function indicates better bowel function. Sexual function is a measure of sexual function and sexual satisfaction. The score ranges from 5 to 37, higher a score indicating better sexual functions. Similar baseline data for UPHS and VA groups is presented in Tables 4 to 6, and that by ethnicity (African American and Caucasian) is presented in Tables 9 to 11.

Table 4: Overall General Health and Prostate Cancer Index (n=156) at the baseline

Variable	Mean (standard deviation)		
General Health			
Physical functioning	27.5 (4.8)		
Role-physical	7.2 (1.4)		
Social function	6 (1)		
Bodily pain	3.3 (1.9)		
Vitality	15.2 (2)		
Mental health	20.7 (2.4)		
UCLA Prostate Cancer Index	K		
Urinary function	10.5 (1.3)		
Bowel function	15.9 (1.6)		
Sexual function	25.3 (7.9)		

Table 5: Functional Status and Prostate Cancer Index (n=156)

Variable			Percent		
General Health					
In general, would you say	9.5%				
		Very good	32.7%		
		Good	26.9%		
		Fair	7.7%		
		Poor	3.2%		
Compared to one year ag in general now?	o, how would you	rate your health			
Much b	etter now than one	year ago	29.5%		
Somewl	hat better now than	one year ago	32.7%		
About th	e same as one year	r ago	26.9%		
Somewh	at worse now than	one year ago	7.7%		
Much we	orse now than on y	ear ago	3.2%		
UCLA Prostate Cancer I	ndex		•		
Urinary bother: No p	roblem		69.4%		
Very	small problem		14.9%		
Small	l problem		8.2%		
Mode	erate problem		4.1%		
Big p	roblem		3.4%		
Bowel bother: No p	roblem		0.0%		
Very	small problem		0.4%		
Small	problem		6.1%		
Mode	erate problem		15.5%		
Big p	roblem		75.0%		
Sexual bother: No 1	problem		49.7%		
Very	small problem		9.8%		
	ll problem		13.9%		
Mod	erate problem		13.9%		
Big p	oroblem		12.6%		

Table 6: Comparison of demographics across VA and UPHS groups at the baseline (n=156)

Variable	UPHS (n=130)	VA(n=26)	
Race			
White	93.4%	6.6%	χ=39.3
African American	48.6%	51.4%	p=<.0001
Education			
8 grades or less	50.0%	50.0%	χ=24.4
Some high school	54.4%	45.6%	p=.0004
High school graduate	70.3%	29.7%	1
Some college	80.7%	19.4%	
College graduate	95.2%	4.8%	
Advanced or graduate training	98.0%	2.0%	
Marital status			
Married	90.2%	9.8%	χ=22.0
Single	60.0%	40.0%	p=<.0001
Widowed	66.7%	33.3%	
Divorced	50.0%	50.0%	
Current employment status			
Working full-time	95.1%	4.9%	χ=22.4
Working part-time	87.5%	12.5%	p=.0002
Retired	64.2%	3.9%	P .0002
Other	80.0%	20.0%	
Household income			
Under \$10,000	50.0%	50.0%	χ=69.2
\$10,001 up to \$20,000	21.4%	78.6%	p=<.0001
\$20,001 up to \$30,000	66.7%	33.3%	•
\$30,001 up to \$40,000	84.6%	15.4%	
\$40,001 up to \$50,000	75.0%	25.0%	
\$50,001 up to \$70,000	100.0%	0.0%	
\$75,001 or more	100.0%	0.0%	

Table 7: Comparison of overall general health and PCI of VA and UPHS groups at baseline

Variable	UPHS (n=130)	VA (n=26)	p value
Physical functioning	28.5 (sd.=3.7)	22.5(sd.=6.7)	<.0001
General Health			
Role-physical	7.4 (sd.=.2)	6.1 (sd.=1.9)	<.0001
Social function	6.1 (sd.=1.0)	5.6 (sd.=0.9)	.0650
Bodily pain	3 (sd.=1.6)	4.84 (sd.=2.5)	<.0001
Vitality	15 (sd.=2)	15.8 (sd.=1.9)	.0864
Mental health	21 (sd.=2.5)	20.9 (sd.=1.7)	.6254
UCLA Prostate Cancer Index			
Urinary function	10.6 (sd.=1.2)	9.9 (sd.=1.5)	.0130
Bowel function	15.9 (sd.=1.5)	15.4 (sd.=1.8)	.1228
Sexual function	25.8 (sd.=7.7)	22.8 (sd.=8.9)	.1287

Table 8 Comparison of functional status and PCI of VA and UPHS at the baseline

Variable		UPHS (n=130)	VA (n=26)	
General Health				
In general, would	you say your health is			
	Excellent	97.8%	2.2%	$\chi = 33.9$
	Very Good	92.2%	7.8%	p=<.0001
	Good	71.4%	28.6%	
	Fair	58.3%	41.7%	
	Poor	20.0%	80.0%	
Compared to one rate your health in	year ago, how would you general now?			
Much better nov	v than one year ago	60.0%	40.0%	
Somewhat better	r now than one year ago	84.6%	15.4%	χ=3.6
About the same	as one year ago	85.7%	14.3%	p=.4580
Somewhat worse	e now than one year ago	81.2%	18.7%	
Much worse no	w than on year ago	66.7%	33.3%	
UCLA Prostate Ca	ancer Index			
Urinary bother	No problem	87.3%	12.7%	
	Very small problem	77.3%	22.7%	$\chi = 7.0$
	Small problem	58.3%	41.7%	p=.1346
	Moderate problem	83.3%	16.7%	
	Big problem	80.0%	20.0%	
Bowel bother	No problem	0.0%	0.0%	
	Very small problem	80.0%	20.0%	χ=6.9
	Small problem	55.6%	44.4%	p=.0744
	Moderate problem	73.9%	26.1%	
	Big problem	86.5%	13.5%	
Sexual bother	No problem	84.5%	15.5%	χ=3.1
	Very small problem	85.7%	14.3%	p=.5398
	Small problem	70.0%	30.0%	-
	Moderate problem	85.0%	15.0%	
	Big problem	88.9%	11.1%	

Table 9: Comparison of demographics across ethnicity at the baseline

Variable	Caucasian (n=121)	African-American	
	(11 121)	(n=35)	
Education			
8 grades or less	50.0%	50.0%	χ=23.0
Some high school	36.4%	63.6%	p=.0008
High school graduate	68.8%	35.2%	
Some college	80.7%	19.3%	
College graduate	85.7%	14.3%	
Advanced or graduate training	92.0%	8.0%	
Marital status			
Married	84.6%	15.4%	$\chi = 21.0$
Single	70.0%	30.0%	p=.0001
Widowed	50.0%	50.0%	
Divorced	37.5%	62.5%	
Current employment status			
Working full-time	88.9%	11.1%	$\chi = 18.5$
Working part-time	75.0%	25.0%	p=.0010
Retired	66.0%	34.0%	
Other	40.0%	60.0%	
Household income			
Under \$10,000	50.0%	50.0%	$\chi = 48.3$
\$10,001 up to \$20,000	21.4%	78.6%	p=<.0001
\$20,001 up to \$30,000	53.3%	46.7%	1
\$30,001 up to \$40,000	84.6%	15.4%	
\$40,001 up to \$50,000	75.0%	25.0%	
\$50,001 up to \$70,000	82.6%	17.4%	
\$75,001 or more	95.7%	17.4%	

Table 10: Comparison of mean scores of general health and PCI across ethnicity at the base line

Variable	Caucasian (n=121)	African American (n=35)				
General Health						
Physical functioning	28.3 (sd.=4.4)	24.8 (sd.=5.6)	.0005			
Role-physical	7.4 (sd.=1.2)	6.5 (sd.=1.8)	.0017			
Social function	6.1 (sd.=1.1)	5.6 (sd.=.79)	.0232			
Bodily pain	3.0 (Sd.=1.7)	4.3 (sd.=1.9)	.0003			
Vitality	14.9 (sd.=1.9)	16.2 (sd.=2.2)	.0024			
Mental health	20.7 (sd.=2.6)	20.7 (sd.=1.8)	.9381			
UCLA Prostate Cancer Index						
Urinary function	10.6 (sd.=1.3)	10.4 (sd.=1.2)	.6422			
Bowel function	25.9 (sd.=1.6)	15.9 (sd.=1.5)	.8526			
Sexual function	25.6 (sd.=8)	24.3(sd.=7.2)	.4156			

Table 11: Comparison of functional status and PCI across ethnicity at the baseline

Variable		Caucasian (n=121)	African American (n=35)	
General Health			-	
In general, would	you say your health is Excellent Very Good Good Fair	89.1% 90.2% 59.5% 41.7%	10.9% 9.8% 40.5% 58.3%	χ=29.9 p=<.0001
rate your health in Much better no Somewhat bet About the sam Somewhat wo Much worse n	ow than one year ago ter now than one year ago te as one year ago rse now than one year ago ow than on year ago	80.0% 40.0% 69.2% 80.6% 75.0% 89.3%	20.0% 60.0% 30.8% 19.4% 25.0% 16.7%	χ=5.2 p=.2601
UCLA Prostate C Urinary bother	No problem Very small problem Small problem Moderate problem Big problem	80.4% 63.6% 66.7% 83.3% 100.0%	19.6% 36.4% 33.3% 11.7% 0.0%	χ=5.3 p=.2580
Bowel bother	No problem Very small problem Small problem Moderate problem Big problem	0.0% 100% 55.6% 65.2% 80.2%	0.0% 0.0% 44.4% 34.8% 19.8%	χ=6.3 p=.0991
Sexual bother	No problem Very small problem Small problem Moderate problem Big problem	84.5% 64.3% 65.0% 75.0% 83.3%	15.5% 35.7% 35.0% 25.0% 16.7%	χ=5.7 p=.2218

### Task 7: Indirect Cost Data Abstraction Design (Appendix b)

A survey to obtain indirect cost data was developed and sent out to all recruited patients at post diagnosis follow up period.

### Task 8: Abstraction of Medical Records

- a. Medical record abstractions is currently being performed and will continue during the follow-up period.
- b. Data entry and quality control measures are ongoing.
- c. Follow-up interviews and data collection are being done at every three months.

### Task 9: Data entry and coding

- a. Data dictionary was created
- b. Database was set up in Microsoft Access
- c. All the data obtained is being coded (ongoing).
- d. All the data is being entered (ongoing).
- e. As of today our database consist of baseline QOL data on 156 patients.

### **KEY RESEARCH ACCOMPLISHMENTS**

During the past eleven months we have established the recruitment and follow up program. We have successfully recruited total of 292 newly diagnosed prostate cancer patients from the urology clinic, radiation oncology clinic and VA medical center. Patient recruitment, data collection on Quality of Life, Satisfaction with Care, Direct and indirect medical cost at baseline and follow-up is currently ongoing. Upon recruitment each patient is offered \$10 in compensation and each follow-up \$5 is offered upon completion of surveys. We have found this to be helpful in generating good response rates. Also, another important observation is that involvement of urologist has greatly enhanced the recruitment and retention of patients.

#### REPORTABLE OUTCOMES

- 1. Presented an abstract at the Gerontological society of America (Appendix C) Jayadevappa R, Chhatre S, Boyle J, Kvam K, Bloom BS, Malkowicz. Variations in Cost of Prostate Cancer Across Age and Ethnicity. The Gerontologist. 55<sup>th</sup> Annual Scientific Meeting "Relationships in a Changing World: From Aging Cells to Aging Societies", Volume 42, 1, October 2002.
- 2. Under review- a long term study on cost effectiveness of prostate cancer treatment and disease progression entitled "Cost Effectiveness of Prostate Cancer Treatment Across Age and Ethnicity" Applied to: The American Cancer Society Research Scholar Grant.

Study start date: 07/01/2003 End Date: 06/30/2007

Principal Investigator: Ravishankar Jayadevappa, Ph.D.

- 3. Jayadevappa R, Malkowicz B, Weinder M, Chhatre S, Bloom BS. Direct Medical Care Cost of Patients with Prostate Cancer Across Age and Ethnicity. (working paper) (brief description of the article is shown in Appendix D)
- 4. Under review- a Collaborative Center grant entitled "Quality of Life in Long Term Survivors of Prostate Cancer" the Abramson Cancer Center, Collaborative Pilot project Program.

Start Date: 06/01/2003 End Date 05/31/2003

Principal Investigator: Ravishankar Jayadevappa, Ph.D.

#### CONCLUSIONS

Most of the proposed targeted activities were achieved in the year. We have a well-established recruitment and retention mechanism in place. The support of Urologist has been very helpful toward this. As of now, we have recruited 292 newly diagnosed prostate cancer patients. We will aim to achieve our goal of recruiting equal number of African Americans in the coming month. The process of data entry and data quality control is established and is ongoing. In addition, we have been able to publish and present the preliminary information. We have also used this as a foundation for developing two proposals on prostate cancer to the American Cancer Society and Cancer Center Collaborative Program.

### Appendix A

## PROSTATE CANCER PROJECT MEDICAL RECORDS ABSTRACTION SHEET

	Date of Record Abstraction/
(1)	Medical Record #
	Patient unique ID #
(3)	Date of Birth/_/
(4)	Marital status: $1 = \text{married } \square$ $2 = \text{single } \square$ $3 = \text{widowed } \square$ $4 = \text{divorced } \square$
(5)	Ethnicity: $1 = A frican American \square 2 = White \square 3 = Hispanic \square 4 = other \square$
(6)	Mortality (Last progress note) Yes No
	Pre-hospital living arrangement
	$1 = Nursing home $ $\square$ $2 = Care facility other than nursing home \square$
	$3 = In \ Community \ with \ wife/husband \ \square \ and/or \ care \ giver \ \square$
	$4 = Lives \ alone \ \Box$ $5 = Don't \ know \ \Box$
(8)	Health Insurance
	$1 = Medicaid$ $Yes \square$ $No \square$ $2 = Medicare$ $Yes \square$ $No \square$
	$3 = Managed Care  Yes \square  No \square \qquad 4 = Private \qquad Yes \square  No \square$
	5 = None
(9)	Date of First Prostate Cancer Diagnosis//
(10)	) PSA Score Before After (11) TNM Stage
(12)	) Indicate histological score on Gleason (2-10)
(13)	Are pelvic lymph nodes involved? $1 = Yes \square 2 = No \square 9 = unknown \square$
(14)	) Stage this patient on the MD Anderson Staging
	Staging Classification (use highest grade listed) A B
	(A) $1 = \text{Group I}$ (B) $1 = \text{well diff.}$
	2 = Group II $2 = Mod. Diff.$
	3 = Group III $3 = Poorly diff.$
	4 = Group IV

(15) Stage this patient on the American Urological Staging scale
1 = Stage A1 Focal 2 = Stage A2 Diffuse
3 = Stage B1 confined to prostate, small Discrete nodule
4 = Stage B2 confined to prostate, nodule > 1.5 or multiple nodules
5 = stage C1 tumor 70g or less, locally advanced disease; no involvement of seminal vesicles
6 = stage C2 tumor >70g; involvement of seminal vesicles
7 = stage D1 pelvic lymph node metastases or urethral obstruction causing hydronephorosis
8 = stage D2 Bone or distant lymph node or organ or soft tissue metastases
(16) Change in PSA score and Stage: $1 = \text{Yes} \square$ $2 = \text{No} \square$ $9 = \text{unknown} \square$
If Yes, What is the current PSA score:
PSA Score and stage at subsequent diagnosis:and
PSA score and Stage at 3 months (after diagnosis):and
PSA score and Stage at 6 months (after diagnosis):and
PSA score and Stage at 9 months (after diagnosis):and
PSA score and Stage at 12 months (after diagnosis)and
PSA score and Stage at 15 months (after diagnosis) and
PSA score and Stage at 18 months (after diagnosis) and
PSA score and Stage at 21 months (after diagnosis) and
PSA score and Stage at 24 months (after diagnosis)and
PROCEDURES (TYPE OF TREATMENT)
(17) Radiation Tx -Type 1=Yes $\square$ 2 = No $\square$ If yes, specify
$I = external\ beam\ \square$ $2 = interstitial\ \square$ $3 = extended\ filed\ \square$
(18) Amount of RADS
(19) Surgery: $1=Yes \square$ $2=No \square$ If yes, specify
1 = Pelvic LN dissection
$3 = Orchiectomy$ $\square$ $4 = Radical Prostatectomy$ $\square$
(20) Hormone therapy: $1=Yes \square$ $2=No \square$ If yes, specify
(21) Watchful waiting $1=Yes \square$ $2=No \square$ If yes, specify
(22) Other procedures or treatments: $1=Ves$ $2=No$

**DIAGNOSTIC STUDIES**  $1=Yes \square$   $2=No \square$ (23) Bone scan: 1 = + for bone mets  $\square$   $2 = \text{neg } \square$   $3 = \text{not done } \square$ If yes,  $1=Yes \square$   $2=No \square$ (24) CT Scan of Pelvis: 1 =+ for lymph node mets  $\square$  2 = neg  $\square$  3 = not done  $\square$ If yes,  $4 = \text{Local invasion to seminal vesicle(s) or bladder} \square 5 = \text{other} \square$ (25) Relevant Medical Diagnosis: Yes \(\bigcup \) No \(\bigcup \) If yes check all that apply: 1 = Depression  $\square$  2 = Stroke  $\square$  3 = Parkinsonism  $\square$  4 = Dementia  $\square$ 5 = UTI  $\bigcirc$  6 = Urethritis  $\bigcirc$  7 = Asthama  $\bigcirc$   $8 = Arthritis of knees or hips <math>\bigcirc$ 9 = Diabetes mellitus  $\square$  9 = CHF/MI heart troubles angina  $\square$ 0 = COPD  $\square$  11 = Cancer  $\square$  12 = Other (e.g., M.S., neurological)  $\square$ Other(s) (26) Relevant medications at the time of review: Yes \(\bigcup \) No \(\bigcup \) If yes check all that apply List all the Prescribed Medications (at baseline): *List all the Prescribed Medications (After):* 

If yes, specify

## Appendix B INDIRECT COST

Please complete the following section related to your expenses that are not covered by your health insurance (Note: please use only expenses that are attributable to prostate cancer).

### I Direct non Medical Cost:

1. During the last three months have you incurred any out of pocket expenses on
prescribed and non-prescribed medication (s)? $1=Yes$ $\square$ $2=No$ $\square$
If yes,
(A) Monthly average expenses on prescribed medications
(B) Monthly average expenses on non-prescribed medication (includes any over the counter and pain medications)
2. Monthly average parking expenses during your inpatient and outpatient visit (s) in the last three months
3. Monthly average transportation expenses during inpatient and outpatient visit(s) cost in the last three months
4. Monthly average expenses of meals outside home that are directly attributable to your prostate cancer during the last three months
5. Monthly expenses associated with care giver (s) (includes: spouse, children, or other) during the last three months
6. Other out of pocket expenses that are not specified above (please specify the amount and type)
II. Patient and care giver(s) time
Do you take more time now to do the following activities?
(1) Traveling $1=Yes \square$ $2=No \square$
If yes, total additional time needed for all of your daily and leisure traveling activities
(2) Did you miss work or have decreased your work hours? $1=Yes$ $\square$ $2=No$ $\square$

if yes, total number of days of work missed in the last three months				
total number of decreased work hours in the last three months				
(3) Do you now take more time to do the usual house work? $1=Yes \Box \qquad 2=N_0 \Box$				
If yes, additional time needed				
(4) Do you now need more help from your care givers (spouse, children or others)				
$1=Yes$ $\square$ $2=No$ $\square$				
If yes, additional time provided by your care giver(s) everyday				

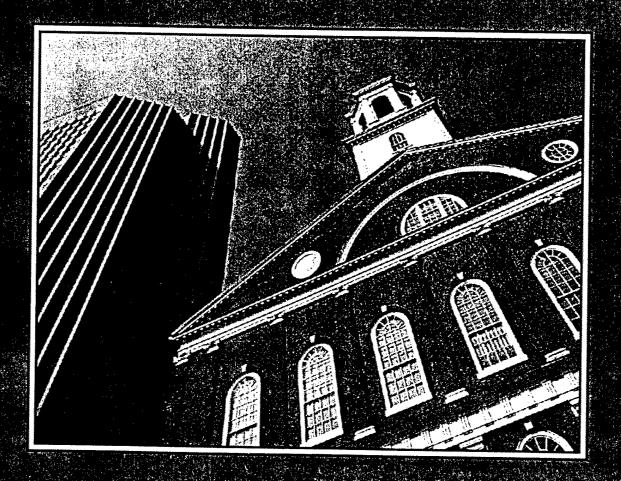
## Appendix C

# THE GERONIOLOGIST

IN THIS ISSUE:

PROGRAM ABSTRACTS
55th Annual Scientific Meeting
"Relationships in a Changing World:
From Aging Cells to Aging Societies"

VOLUME 42 SPECIAL ISSUE I OCTOBER 2002



provides a framework for future phases of the project and has laid important groundwork for in-depth research in understanding communities in general from a multitude of perspectives.

## UNDERSTANDING WHY AFRICAN AMERICANS PARTICIPATE IN RESEARCH

T. Perkins, M. Perkinson, Washington University School of Medicine, St. Louis, MO.

Recruiting African Americans for research presents special challenges for investigators. This study addresses African Americans' attitudes toward participation in health-related research. Ten community leaders and researchers who had professional experience working with African Americans were interviewed regarding recruitment barriers and research benefits for the older African American population. In addition, thirty-seven African American spousal caregivers of frail, older husbands were interviewed regarding their participation in a caregiving study. Primary reasons for participation in health-related research included the desire to obtain information on caregiving and health issues, help others, and talk to someone. A better understanding of the reasons African Americans participate in health-related research projects and the aspects of participation they find most satisfying is an essential step toward developing more effective recruitment strategies for this population.

## VARIATIONS IN COST OF PROSTATE CANCER ACROSS AGE AND ETHNICITY

R. Jayadevappa, S. Chhatre, J. Boyle, K. Kvam, B. Bloom, B. Malkowicz, University of Pennsylvania, Philadelphia, PA. Objective: To determine variations in treatment type and direct cost of prostate cancer across two ethnic and age groups (< 65 and 65). Methods: Retrospective Cohort Control Design. We randomly selected 120 prostate cancer patients (sixty African Americans and sixty Caucasians), treated between 1997-2001 in an academic medical center. Control group consisted of 240 patients without prostate cancer, matched by ethnicity, age, and Charlson comorbidity score. Results: Average incremental cost of prostate cancer was \$2,532 for African Americans and \$3,682 for Caucasians. Average incremental cost of prostate cancer treatment for elderly was 7% higher than younger patients. Average cost of prostate cancer treatment for elderly African Americans was 50% higher than younger patients, whereas for Caucasians, this was 32% lower. Charlsons Comorbdity scores were more than 2-fold greater for African Americans than Caucasians (4.5 vs 2). 58% of African Americans received radiation compared to 42% of Caucasians; 51% of African Americans and 67% of Caucasians received surgery; 47% of African Americans received hormone therapy compared to 34% of Caucasians. Results indicate that ethnicity, age, comorbidity and disease stage importantly affect cost of care and type of treatment received by prostate cancer patients.

### PSYCHOMETRIC EVALUATION OF THE GERIATRIC DEPRESSION SCALE USING AN ASIAN AMERICAN ELDERLY SAMPLE

A. Mui, S. Kang, L. Chen, Columbia University, New York,

This study is based on a regionally representative sample of 407 Asian American elders who belong to one of the following six ethnic groups: Chinese, Korean, Indian, Filipino, Vietnamese, or Japanese. The Interviews were conducted in English, Chinese, Korean, Hindi, Tagalog and Vietnamese. In order to evaluate the cross-cultural utility of the Geriatric Depression Scale (GDS), the present study examined it's the psychometric properties. The analyses on the whole Asian elderly sample indicated that the Cronbach's alpha coefficient of the GDS was .90 and the split-half reliability coefficient was .80. The Cronbach's alpha coefficients of the CDS for the six Asian subgroups ranged from .85 to .92 and the spilt-half reliability coefficients ranged from .76 to .86. The data suggested that the GDS has good internal consistency and acceptable reliability for use among the Asian American elderly population.

97

### SUCCESSFUL AGING

### LIVING PAST A HUNDRED

D. Marchese, Films for the Humanities & Sciences, Princeton, NJ.

One (57 minutes, color) videotape/1999 Over the course of the 20th century, the life span in the West has doubled. What will be the impact of increasing longevity on society, the environment, and the global economy? Combining commentary from leading scientists with case studies of centenarians from the U.S. and around the world, this documentary examines elements that influence life expectancy—diet, fitness, physical and mental health, sexuality, and even plastic surgery—and considers the long term implications of increased longevity.

## LEARNING TO FLY: THE WINGS OF POSSIBILITIES

L. Kussmann, Aquarius Productions, Sherborn, MA.

The acclaimed author of Fire in the Belly presents an exhilarating look at the flying trapeze and at the potential offers for growth and transformation. Learning to Fly teach us to soar on the wings of possibility. As we watch Sam Ke and fellow student progress through breathtaking exercises. Keen imparts moving revelations about risk taking, trust, bravado, true strength, falling and letting go. 1999 Part3: AGELEEARN Run Time: 1999, 28 minutes, Price: \$90 Offen Recipient, Best of the Silver Images Film Festival 2002, Documentary What the Media is Saying... "Sam Keen is of our liveliest minds. It's a joy to go with him as a guide the byways of the soul in search for greater meaning in the Daniel Goleman, Author of Emotional Intelligence

### Appendix D

### Direct Medical Care Cost of Patients with Prostate Cancer Across Age and Ethnicity

- (a) Introduction and Objective: Prostate cancer (PC) is the leading cancer among men in the US and a major health problem in the elderly. Cost and utility of health status is relevant to many health conditions, the multiple treatment options for PC provide a unique arena for examining the costs and resource utilization of care. Objective of the paper was to analyze cost and resource utilization of PC patients by age and ethnicity.
- **(b) Methods:** This was a retrospective cohort control study. Sample consisted of 120 randomly selected African Americans and Caucasians, 40 years, diagnosed and treated for prostate cancer between 1997-2000 at an urban academic hospital with at least two years of enrollment in the health system. The controls were 240 patients from the same database, matched by age, ethnicity and Charlson co-morbidity score (CHS). Demographic, clinical and direct cost data was obtained from medical chart review and the Pennsylvania Integrated Clinical and Research Database. Costs were defined as actual charges for specific services, we used an average cost to charge ratio of .80. Costs attributed to prostate cancer were identified using ICD and CPT codes. Demographics and clinical variables were compared using t-test and chi-square. Total, incremental and prostate cancer costs per patient over three years was compared between groups. Log linear regression models were used to analyze the factors associated with total cost.

Table 12: Characteristics of Prostate cancer patients

Variables	African American (n=60)	Caucasians (n=60)
Mean age (years)	72.63 (sd=12)	69 (9.5)
Charlson score	4.5 (sd=3.35)	2 (sd=2.4)
Marital status  Married  Single  Widowed  Divorced	37 (61.7%) 10 (16.7%) 8 (13.30%) 4 (6.70%)	47 (79.70%) 8(13.60%) 1 (1.70%) 2 (3.40%)
Health Insurance Medicare Managed care Private Medicare-Managed care Medicare-Medicaid	3 (6%) 16(27%) 2(3%) 38((64%)	5 (8%) 32(54%) 1(1%) 20(34%) 1 (1%)
Deceased	14 (23%)	7 (12%)

(c) Results: As shown in table 12, the mean age of African American prostate cancer patient was 73 yrs, and mean Charlson co-morbidity score was 4.5. For Caucasians, it was 69 yrs and 2 respectively. The difference in Charlson co-morbidity score was statistically significant. Marital and health insurance status was comparable. African Americans had higher PSA at diagnosis (19.4) than Caucasians (13.6). Mean Gleason scores (6.7) were comparable across two ethnic groups. Treatments for prostate cancer varied by age and ethnicity (table 3). Log regression of total sample showed that prostate cancer patients had 57% higher total direct medical cost. While Charlson Co-morbidity score was positively associated with cost, age and ethnicity were not. Log linear regression model for the prostate cancer group showed ethnicity and Charlson co-morbidity were associated with cost.

Table 13: Disease characteristics of patients

Variables	African American (n=60)	Caucasians (n=60)
PSA score (at the time of diagnosis)	19.4 (sd=28.5)	13.6 (sd=20.2)
PSA score (post treatment)	3.1 (sd=10.3)	.94 (sd=1.6)
Gleason score (average)	6.7 (sd=1.66)	6.5 (sd=1.21)
Lymph node involved-yes	5 (8.3%)	2 (3.4%)

Table 14: Treatment and cost of prostate cancer

	African American (n=60)		Caucasians (n=60)	
	< 65 yr	65 yr	< 65 yr	65 yr
Radiation (%)	17	67	24	53
Surgery (%)	75	47	91	58
Hormone therapy(%)	31	51	19	47
Mean total cost of PC patients (\$)	19,628	19,710	18,038	22,511
Mean PC cost (\$)	5,731	4,833	7,907	6,727
Mean incremental cost(\$)	1,134	1,126	11,529	5,165

**d)** Conclusions: African American prostate cancer patients have higher co-morbidity and lower incremental cost. Charlson co-morbidity, age, and ethnicity are important factors associated with the cost of care and type of treatment received.